

Should doctors intentionally do less than the best?

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Abstract

The papers of Burley and Harris, and Draper and Chadwick, in this issue, raise a problem: what should doctors do when patients request an option which is not the best available? ^{1 2} This commentary argues that doctors have a duty to offer that option which will result in the individual affected by that choice enjoying the highest level of wellbeing. Doctors can deviate from this duty and submaximise—bring about an outcome that is less than the best—only if there are good reasons to do so. The desire to have a child which is genetically related provides little, if any, reason to submaximise. The implication for cloning, preimplantation diagnosis and embryo transfer is that doctors should only produce a clone or transfer embryos expected to enjoy a level of wellbeing which is less than that enjoyed by other children the couple could have, if there is a good reason to employ that technology. This paper sketches what might constitute a good reason to submaximise.

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Political liberties and the goals of medicine

There is a difference between when we are entitled to interfere in the actions of a competent individual for his or her or other people's good (the limits of political non-interference) and what we should do for that person. People may be allowed to smoke, but that does not imply that we should give them cigarettes. People may smoke because of their right not to be interfered with, not because smoking is a good thing. The goal of medicine is to promote wellbeing through health care. A woman might be allowed to carry an anencephalic fetus to term, but should doctors implant embryos if they know that they are at high risk of anencephaly, even if parents request it? Burley and Harris argue that, even if cloning results in an individual whose life will be worse than the life of a non-cloned individual, this may not be a reason to ban or prevent people from cloning.¹ This is right. In a similar way, we allow individuals to make all sorts of decisions which are

bad for them, and sometimes for their children. But *should* doctors accede to a request to clone? This raises a general issue: how should doctors respond when individuals request medical assistance to bring about an outcome that is less than optimal?

It is worth noting the implications of this distinction between liberty and normative reasons for prenatal diagnosis and embryo transfer. It is often stated that genetic counselling should be non-directive. Draper and Chadwick ask whether the same principles will apply to preimplantation diagnosis and embryo transfer.² In prenatal diagnosis, parents might be told that they have a fetus with Down's syndrome but left to decide for themselves whether to terminate. This does not imply that an embryo with Down's syndrome has the same value as one with a normal karyotype. Nor does it imply that doctors should transfer an embryo with Down's syndrome in preference to a normal embryo. Transfer of embryos requires that doctors act. This requires that they make a normative judgment about the rightness of that act, which has a different significance for what they should do compared to their judgments of what parents should do. Doctors cannot and should not force couples to have a termination of pregnancy for some serious genetic condition, but they might decide not to assist couples to have a child suffering from such a condition.

Medicine's commitment to maximisation

Should doctors clone if it will result in a child who has less wellbeing than a non-cloned child, which the parents could have?

The primary axiom of medical practice is to do what is in the best interests of the patient. There are constraints: how interests are to be determined (and how patients are to be involved in this) and respect for autonomy. However, if one treatment offers ten years of good life, and another five years of good life, doctors have an obligation to recommend and only to offer the former, other things being equal. Doctors have a commitment to try to maximise wellbeing.

What about when the choice is between different existing individuals? For example, imagine that A and B both have a disease which will be fatal without treatment. With treatment, A will live for ten years, enjoying a good quality of life; B will live for one year of poor quality. Other things being equal, doctors should give priority to treating A.

Sometimes, doctors are confronted with the choice between bringing different individuals into existence. Imagine that doctors are considering which of two embryos to implant. They know that A will have a long life of high quality; B will have a shorter, lower quality of life. Doctors should transfer the one which will have the better life. Indeed, this is already done in *in vitro* fertilisation, when an assessment is made as to which embryo looks "healthiest" of those which are available, and it is transferred in preference to other embryos.

Medicine has a commitment to bringing about the best outcome. If this were medicine's only commitment, then doctors should not clone (in so far as a cloned person's life would be worse than that of a non-cloned person).

This has implications beyond cloning. Draper and Chadwick² imagine some examples in which, on the basis of preimplantation diagnosis, doctors are asked to transfer embryos which are likely to result in lives which are worse off in terms of wellbeing than other lives they could have brought into existence. According to the principle of maximisation, doctors should only transfer the best embryos. When I refer to the "best embryo," I mean the embryo expected to have the life containing the most wellbeing, from its own perspective. Whether deafness, paralysis or mental retardation reduce wellbeing may seem controversial. In part, the answer depends on the conception of wellbeing employed. But for some states, such as permanent unconsciousness or severe mental retardation, it is possible to say that that life has less wellbeing and is a worse life than the average, regardless of the conception of wellbeing employed. It is uncontroversial that a life with cystic fibrosis or some other serious illness is worse than a life without cystic fibrosis, other things being equal.

Less than the best

Are there ever occasions in which doctors should actively participate in bringing about less than the best outcome?

The answer turns on whether there is most reason for doctors to do what these parents and patients are requesting. The theory of reasons for action which I favour is a variant of Derek Parfit's

Critical Present-aim Theory. Elsewhere,³ I have argued that according to the Critical Present-aim Theory:

- for a choice or act to be rational, the state of affairs promoted by that choice or act must be worth promoting. That is, it must promote some objectively valuable state such as wellbeing, achievement, knowledge, justice, and so on.
- the state of affairs promoted must have an expected value which is good enough relative to other available alternatives.
- we are not rationally required to give up a concern for one objectively valuable state which is good enough for a relevantly different state which is more valuable. Some present rational concerns are good enough.

The Present-aim Theory gives some weight to *what agents now actually care about*. I argued that an individual can have most reason to promote a state of affairs which has less value than other states of affairs which she could promote. These and other arguments may imply that doctors can intentionally do less than the best if:

1. the outcome is good enough for *prima facie* consideration. Doctors should not, for example, transfer embryos which will have Tay Sach's disease, because that condition is so bad that it arguably makes life not worth living. At any rate, the life of an embryo with Tay Sach's disease is expected to be much worse than the life of a normal embryo.
2. promoting the suboptimal outcome is not more expensive than promoting the optimal outcome. In publicly funded health care, distributive justice requires that individuals do not consume more than their fair share of resources.⁴ Do the life-time costs of caring for disabled infants count in these decisions? The life-time care costs for severe mental retardation would be a reason for doctors not to implant such an embryo, even if the child's life would be worth living, if a normal embryo could be implanted.
3. there is a good reason for parents or patients choosing the suboptimal outcome.

What might constitute a good reason for promoting a suboptimal outcome? The reason cannot be only that the parents strongly desire it. Doctors should not provide mutilating, painful clitorrectomy unless there is a good reason to do so, even if the patient requests it. We are considering reasons which apply to doctors and parents, and

not the motivations of the parties concerned (and what people believe to be their reasons). For example, there is a reason to bring into existence a child who will have a long happy life rather than one of profound suffering. This is true even if parents might want a child who will experience great suffering rather than one who will have a happy life.

In health care in general, the importance given to personal liberty and autonomy might provide reasons justifying some degree of submaximisation. In reproduction, any claim on medical assistance has to do with reproductive rights (rather than liberties). It is far from clear how much assistance individuals are entitled to claim. Moreover, it is far from clear that parents also have "a right" to an option which results in the birth of a child with less prospect of a rewarding life.

Political statement

That said, submaximisation in reproduction might be justifiable for other reasons. Burley and Harris discuss mixed-race marriages. Imagine that a black man and a white woman are infertile and have IVF with donor gametes. They want an embryo which will result in a black child. Because they live in a racist society, their child's life will be harder than that of a white child. But they want to make a political statement about racial equality. They want to make a statement of the equal value of people from different races. This is a good reason to have a black child. And in so far as that child's life would be worth living, there can be no objection on the child's part to having been brought into existence. Any white child they might have had would have been a different child.

Draper and Chadwick question whether parents should be entitled to bring into existence a child with Down's syndrome to effect a political statement, when they could have a normal child. Whether the parents are so entitled turns on whether there is a good reason to make that statement. While there is no difference in value between the lives of people from different races, there is a difference in the value of the life of a person with mental retardation compared to the life of a child of normal intelligence. Race does not necessarily contract the richness of our relationships and our lives in the way mental retardation does. Mental retardation narrows our engagement with the world, puts greater limits on what we can achieve and the richness of our relationships with family and friends, and restricts the degree to which we can live our own life. We have a reason to prefer normal embryos to embryos with conditions which result in mental retardation, in a way

that we do not have a reason to prefer embryos from a particular race. To the extent that any political statement asserts that we have as much reason to bring into existence someone with severe mental retardation as someone with a normal intelligence, it does not provide a good reason for action. This does not preclude parents from having a child with mental retardation for other reasons, such as improving family welfare by increasing financial support or improving the plight of other retarded children in society, which might appeal to a principle of equal consideration of the suffering of all existing individuals. Provided the child's own life would be worth living, these reasons might justify parents' preferences for a retarded child.

Reasons may be relative to an individual's circumstances. Imagine a woman wants a girl rather than a boy. She is also a carrier of the adrenoleukodystrophy gene.⁵ Assume that any affected male will die as a child. Unaffected males will be completely normal. Female carriers will carry a gene, which may be passed on to their children, and they have a ten per cent chance of becoming paralysed in middle age. Preimplantation diagnosis shows that the embryos are: one affected male, two unaffected males and two female carriers. She wants a female carrier transferred. Her reason is that she was sexually abused as a child. She suffers great psychological anxiety when she sees or handles male genitalia. This might provide a good reason to transfer a female carrier rather than an unaffected male, even though the offspring might be paralysed in middle age.

Should doctors clone? If cloning results in a person who has a worse life than a non-cloned individual, medicine's commitment to maximisation raises the question: why should doctors clone? If A will be worse off than B, there must be some other good reason for choosing A besides welfare considerations, if we want to say that doctors should bring A rather than B into existence. If, for example, the clone had some exceptional talent that meant that its life would go very well in one direction, while it might suffer in other directions, this might provide a reason to clone. Van Gogh led a short life marked by mental and physical suffering. It is unclear exactly what mental illness he was intermittently suffering from, and for how long he suffered. Some say that he had periods of severe depression followed by periods of mania accompanied by hallucinations. Others have proposed that he was suffering from epilepsy, paranoid schizophrenia, alcoholism or syphilis.⁶ He led a life punctuated by depression and anguish, often for prolonged periods of time, cul-

minating in his suicide at the age of 37. He also lived in great poverty. During his lifetime he sold only one painting. He was never recognised in his own lifetime to be the genius he was. Among his last words were: "But what's the use?"⁷ Van Gogh was also one of history's greatest painters. He achieved more in six years of painting (and most of his work was produced in three years) than probably any other painter in a similar time.

Van Gogh's life went very well from the perspective of producing great art, but it went badly in other respects. Although Van Gogh's life contained great suffering, his talent and contribution to the lives of others provides a reason to clone him, if he requested it. (But for you and I, there are unlikely to be such reasons to support reproductive cloning.)

Cloning could also be used to promote political values, such as equality. In a society with a gross gender imbalance, cloning a particular sex to redress this gender imbalance would provide a reason to clone.

Should doctors be influenced by reasons for action which go beyond the welfare of the individual concerned? Should they be influenced by the welfare of others or political values? Perhaps, in health care in general, individuals should not be harmed to promote these other goals. We should not take the organs from one person without that person's consent to benefit several other people. But when no individual is harmed by promoting these other values, there is less reason to object to taking them into consideration. Imagine that A, the clone, will be worse off than B, the non-clone, because A will be the object of excessive attention. If A is not harmed by being brought into existence rather than B, that is, A's life is worth living (and, A cannot regret being brought into existence, despite having less than perfect prospects), then why not consider these other values?

Is genetic relatedness a good reason to do less than the best?

The issue of whether doctors should offer services which bring about a worse outcome than could be achieved is not new. A couple who both had cystic fibrosis recently requested in vitro fertilisation (IVF) to have a child of their own. They were awaiting lung transplants and were likely to die before the child reached adulthood. Apart from the risk of pregnancy to the mother, the husband would require testicular biopsy to procure sperm. The anaesthetic required presented grave risks to his health, according to his doctors. Intracytoplasmic sperm injection would also be necessary.

Because both parents had cystic fibrosis, the child would be certain to have that disease. The couple refused to consider using donor sperm. Artificial insemination (AID) would have reduced the risks to the mother of superovulation, eliminated the need for an anaesthetic for the father and would virtually eliminate the risk of the child being affected by cystic fibrosis. It was the superior option: all that IVF had in its favour was that it would provide the couple with a child which was genetically related to them. Should doctors provide IVF rather than AID to this couple?

The major reason why parents like this want to have a child who is going to be worse off than some other child which they could have is because they value genetic relatedness, as Draper and Chadwick imply. If genetic relatedness is a reason for action, we have more reason to clone people who request it than to provide assisted reproduction using donor gametes. After all, cloning ensures the highest degree of genetic relatedness. Is there any rational basis to these beliefs about the value of genetic relatedness?

Why do people value genetic relatedness? One reason may be that they value having children like themselves, or with qualities which they value. Another reason may have to do with beliefs about one's place in history and time, and "living on through one's own children". Or perhaps people have some romantic ideal like producing a monument to their love. Perhaps it is easier to identify with one's own genetic children, and vice versa. These beliefs may be based on facts about us determined by evolution. In Judaism, religious affiliation is inherited from one's genetic mother.

While genetic relatedness may have some instrumental value, it has very little intrinsic value. Consider the following example. Jim and Tom are dizygous twins who are very alike genetically but not genetically identical (say, by some fluke, they share 95% of their genes instead of the usual 50%). They marry dizygous twins who are likewise very similar in their genetic relation, Julie and Tessa. They live in the same neighbourhood and do the same kind of work. Both go fishing together on the weekends with their families. Both couples have children at same time. Jim and Julie have Jason; Tom and Tessa have Tim. Jason and Tim are mixed up at birth, unbeknownst to their parents. Jim and Julie raise Tim. Both children turn out to be very similar to each other and study town planning together. When Tim is 18, the hospital informs Jim and Julie of the mix-up. Their child is Jason. Jim is very depressed and angry, not just because he has been deceived, but because he has been deprived of *his* child. There is no good ground for this reaction. Both boys are very alike

in phenotype. Tim is genetically related to Jim (but not as similar as Jason) and has been brought up by Jim. Tim is at least as much if not more *his son* as Jason. Degrees of genetic relatedness do not matter that much.

Genetic relatedness may matter in so far as valuable traits and abilities are heritable. Evidence suggests that intelligence is at least 50% heritable.⁸ If this is so, Einstein or Stephen Hawking have reason to clone themselves or have children of their own because those children are more likely to have at least one valuable trait—intelligence—and as likely to have other valuable traits as children who are genetically unrelated to them.

Are you and I special? Or are we rather ordinary people for whom feelings of preciousness about the value of our own genes are likely to be more difficult to justify? If most of us share a similar range of talents, dispositions, and traits, then there is little reason to believe our children will be better than most. If our genetically related children will suffer some disease, perhaps we should have genetically unrelated children without these diseases.

Reproductive liberty

Is this eugenics? Yes, it is. But not all eugenic practices are objectionable. Killing a fetus with Down's syndrome is eugenics and widely accepted. Wikler has reviewed what is objectionable about eugenics.⁹ What is most objectionable is when the reproductive liberty of people is infringed to promote a perceived good. But we are concerned with putative reproductive rights, rather than liberties here. Unless we believe that people have not only a right to a child, but a right to a child of their own, then not offering them medical assistance to have a child of their own is not an infringement of their rights. This is quite different from the objectionable eugenic practices which occurred in Nazi Germany, America and Europe where people were deemed unfit to reproduce and were sterilised or killed by the state.

We have only been considering choices between different possible children, for example, whether to implant this normal embryo or that embryo with Fragile X (Same Number Choices). More complex issues arise when we consider the choice between having a disabled and no child (Different Number Choices). I will not address Different Number Choices. Doctors have a duty to bring into existence the child who will have the longest and best quality life in Same Number Choices, unless there is a good reason not to. For David King,¹⁰ maximisation is itself an objectionable form of eugenics. In the absence of a good reason

not to maximise, submaximisation is irrational and arguably immoral.

What about the claim that most of us are genetically unique and that is reason enough to have a child of our own?¹¹ It is hard to see the value of genetic uniqueness when that particular uniqueness is not associated with something of value. All rocks are of a unique shape (no two are identical) but that is hardly a reason to get excited about every rock. Diversity and uniqueness for no other reason seems to be of little value.

These claims regarding the overvaluing of genetic relatedness are based on the assumption that parents will come to care about a child who is genetically unrelated to them. Parents have a good reason to save the lives of their own children, rather than other people's children, even if those other children will have longer and happier lives. That is because parents care about their own children to a much greater degree, and that care is based on a special relationship their own children have to them. But there is no such relationship between parents and potential children, genetically related or unrelated.

In a similar way, genetic relatedness may be important in so far as people will suffer depression if they do not have children who are genetically related to them. However, I doubt whether the magnitude of this depression will be so great. Many adoptive parents seem happy enough. Though some may wish that they had had their own genetically related children, they do not seem to suffer serious depression or regret.

On this argument, parents should not be provided with assisted reproduction (cloning or IVF) when the outcome will be a child seriously affected by a genetic disease, such as Fragile X, and a child with better prospects could be produced. In Draper and Chadwick's example of Simon and Claire, doctors should not provide assisted reproduction when the outcome is likely to be a child afflicted with mental retardation, when donor gametes could be used.

According to maximisation, I should bring up Einstein's clone rather than have my own "ordinary" child. This is counterintuitive. Like most other people, I want my own child. But perhaps I should give up my attachment to genetic relatedness. Perhaps I am overly narcissistic. If there is a reason to have my own child, it has to do with the instrumental value of genetic relatedness or the different qualities I have which are of value. Perhaps I have overstated our ordinariness. If so, this would give us reason to have our own children.

Genetic relatedness may have some instrumental value. Perhaps beliefs about its value are

strongly culturally, religiously, or evolutionarily determined and difficult to change. Perhaps they are the source of pleasure and pride in genetic parents. And this may be enough to tip the scales in favour of my own child rather than Einstein's clone.

But there are limits to this instrumental value. Like beliefs about genetic relatedness, beliefs about the value of men compared to women are strongly culturally and religiously determined in some societies. Parents may derive much more pleasure from the birth of a boy rather than a girl in countries such as India and China. The pleasure that parents derive from having the child of their preference is a reason for them to have that child. Interestingly, many liberals are opposed to doctors offering sex selection, even if parents want it, it gives them pleasure and ministers to some cultural value. However, even if we accept sex selection in some circumstances, doctors should not bring into existence a severely disabled male child in preference to a normal female. And so, doctors should not bring a very disabled or sick child into existence when they could bring a child into existence expected to have a long and rewarding life. Whatever the value of genetic relatedness, it is not an unconditional value. Producing an offspring which is genetically related is not itself a good reason to clone.

Conclusion

In the future, genetics will offer us much more information on the nature of embryos and fetuses, and perhaps even gametes. In the case of cloning, we will have more information than ever before on the disease susceptibilities, talents and personality traits of the future individual. Such information will allow us to make fine-grained distinctions about the value of the individuals which would result. We may be able to say that this embryo is likely to have a better life than that. If medicine has an absolute commitment to maximisation,

doctors should only offer to bring into existence those individuals who are expected (based on the information available) to have the best lives. I don't believe that medicine has such a commitment to maximisation. I believe that doctors can intentionally bring about an outcome which is less than the best—but only if there is good reason to do so. Mere genetic relatedness is not, I believe, a good reason for action. An upshot of these arguments is that there may be a more widespread role for using donor gametes in clinical genetics as a way of avoiding genetic disease, at least until gene therapy comes of age.

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